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Patient-reported causes of heart failure in a large European sample☆

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ABSTRACT

Background: Patients diagnosed with chronic diseases develop perceptions about their disease and its causes, which may influence health behavior and emotional well-being. This is the first study to examine patient-reported causes and their correlates in patients with heart failure.
Methods: European heart failure patients ($N = 595$) completed questionnaires, including the Brief Illness Perceptions Questionnaire. Using deductive thematic analysis, patient-reported causes were categorized into *physical*, *natural*, *behavioral*, *psychosocial*, *supernatural* and *other*. Clinical data were collected from medical records.
Results: Patients who did not report any cause (11%) were on average lower educated and participated less often in cardiac rehabilitation. The majority of the remaining patients reported physical causes (46%, mainly comorbidities), followed by behavioral (38%, mainly smoking), psychosocial (35%, mainly (work-related) stress), and natural causes (32%, mainly heredity). There were socio-demographic, clinical and psychological group differences between the various categories, and large discrepancies between prevalence of physical risk factors according to medical records and patient-reported causes; e.g. 58% had hypertension, while only 5% reported this as a cause. Multivariable analyses indicated trends towards associations between physical causes and poor health status (Odds ratio (OR) = 1.41, 95% confidence interval (95% CI) = 0.95–2.09, $p = 0.09$), psychosocial causes and psychological distress (OR = 1.54, 95% CI = 0.94–2.51, p = 0.09), and behavioral causes and a less threatening view of heart failure (OR = 0.64, 95% CI = 0.40–1.01, $p = 0.06$).
Conclusion: European patients most frequently reported comorbidities, smoking, stress, and heredity as heart failure causes, but their causal understanding may be limited. There were trends towards associations between patient-reported causes and health status, psychological distress, and illness perceptions.

1. Introduction

In developed countries, 1–2% of the general population suffers from heart failure, a chronic and debilitating disease characterized by tiredness, shortness of breath and peripheral and/or lung edema, caused by a structural of functional abnormality of the heart [1]. The prevalence of heart failure is still increasing, due to the aging of the population and improved treatment options leading more patients to survive a predisposing cardiac event [2,3]. Nevertheless, heart failure remains associated with an increased risk for morbidity and mortality, impaired health status and frequent hospital admissions [2,3].

After being diagnosed with a disease like heart failure, patients may develop mental representations about the characteristics of their disease (e.g. heart failure) and its causes [4–7]. According to Leventhal's common sense model of self-regulation, these representations are a reaction to situational stimuli (e.g. palpitations, chest pain, or dyspnea), and lead to the adoption of coping strategies. This model also implies that patients evaluate the efficacy of their mental representations and coping strategies in eliminating the situational stimuli, and adjust them if necessary [8]. Therefore, patient-reported causes play a crucial role in disease management, as they can influence if and what type of treatment patients seek, and the actions they take to manage and cope with their disease [6,9–11]. For example, if patients believe their disease was caused by a poor diet, they may be more likely to change their dietary habits.

Previous research has examined patient-reported causes of disease in a variety of patient populations using (purpose-designed) questionnaires or interviews and different coding approaches [12–21]. These studies showed that beliefs held by patients about the causes of their

☆ All authors take responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

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disease are not necessarily consistent with medical and scientific knowledge. Also, it seems that patients with diseases for which causes are less clear (e.g. breast or gynecologic cancer, or chronic fatigue) are more likely to attribute it to external and uncontrollable factors like psychosocial stress factors in the past, and heredity [12,14,16,18], while patients with for example lung cancer, skin melanoma or chronic obstructive pulmonary disease (COPD) more often mention behavioral factors (e.g. smoking), perhaps as a result of common knowledge on the association between these diseases and health behavior [15]. Studies investigating patients with cardiovascular disease (i.e. coronary heart disease and myocardial infarction) also showed considerable variation in patient-reported causes (e.g. stress, lifestyle, health behavior, family history and aging), as well as a lack of concordance between actual risk factors and patient beliefs about causes [13,17,19–21].

To the best of our knowledge, patient-reported causes have never been studied in patients with heart failure. Since heart failure has a chronic and multifactorial nature, better insight into patient-reported causes may provide targets to improve coping behavior and treatment adherence, and enhance patient centered care [17,22]. Therefore, the aims of this study were to 1) describe patient-reported causes in a large European sample of patients with heart failure, 2) examine socio demographic, clinical, lifestyle and psychological correlates of these causes, and 3) examine if patient-reported causes are associated with health status, psychological distress, illness perceptions, and heart failure self-care behavior.

2. Methods

2.1. Study design and participants

The study sample consisted of 595 patients with heart failure, who participated in the large European randomized REMOTE-CIED study [23]. The REMOTE-CIED study was primarily designed to examine the patient perspective on remote monitoring in patients with heart failure with an implantable cardioverter defibrillator (ICD). Patients were recruited from 32 academic and general hospitals in France, Germany, the Netherlands, Spain and Switzerland between April 2013 and January 2016. All patients were between 18 and 85 years of age, suffered from symptomatic heart failure (i.e. left ventricular ejection fraction (LVEF) ≤35% and New York Heart Association (NYHA) functional class II or III at the time of implantation), and received a first-time ICD or cardiac resynchronization therapy defibrillator device (CRT-D) for primary or secondary prophylaxis at one of the participating centers. Patients were asked to complete an elaborative set of standardized and validated questionnaires 1–2 weeks post-ICD/CRT-D implantation. The study protocol was approved by the Medical Ethics Committee of all participating hospitals, and the study was conducted in accordance with the Declaration of Helsinki. All patients received written and oral information about the study and provided written informed consent.

2.2. Measures

Information on *socio demographic characteristics* was collected using purpose-designed questions in the questionnaire, and included age, sex, marital status (single versus having a partner), educational level (secondary school or lower versus tertiary school or higher) and employment status (employed versus unemployed).

Information on *clinical characteristics* was retrieved from patients' medical records at the time of implantation and entered into an electronic case report form by local researchers, and included NYHA functional class, heart failure etiology (ischemic versus non-ischemic), QRS duration, LVEF, atrial fibrillation, hypertension, diabetes mellitus, chronic obstructive pulmonary disease, renal disease (glomerular filtration rate < 60 ml/min/1.73 m^2), and anemia (hemoglobin value <8.6 mmol/l for males and <7.4 mmol/l for females). The 23-item Kansas City Cardiomyopathy Questionnaire (KCCQ) was used to measure *heart failure specific health status*. The KCCQ measures physical limitations, symptoms, social functioning, and health related quality of life (e.g. "Over the past 2 weeks, how much has your heart failure limited your enjoyment of life?"). An overall summary score can be computed (0−100), with higher scores indicating better patient-reported health status. An overall summary score < 50 indicates poor health status. The KCCQ is a valid and reliable tool to assess patient-perceived heart failure specific health status [24]. The internal consistency of the KCCQ was good, with a Cronbach's alpha of 0.98 in the current sample.

Information on *health-related lifestyle characteristics* (i.e. body mass index, smoking status, use of alcoholic beverages, and participation in a cardiac rehabilitation program) was collected with purpose-designed questions in the questionnaire. Additionally, patients completed the 12-item European Heart Failure Self-care Behavior Scale (EHFScBS-12). The items on this scale are rated on a 5-point Likert scale from 1 'completely agree' to 5 'completely disagree' (e.g. "I weigh myself every day"). Total scores can be calculated (12–60), with higher scores indicating worse self-care behavior. This scale is a valid and reliable tool to measure heart failure specific self-care behavior [25], with a Cronbach's alpha of 0.72 in the current sample.

Patients' *psychological status* was assessed using multiple questionnaires. Patients were asked about their *use of psychotropic medication* (i.e. antidepressants, anxiolytics and/or hypnotics) and *psychological treatment* using purpose-designed questions in the questionnaire, as a proxy measure for prior or existing affective disorders. The 7-item Generalized Anxiety Disorder scale (GAD-7) was used to measure *anxiety symptoms*. Items on this scale are rated on a 4-point Likert scale from 0 "not at all" to 3 'almost daily' (e.g. "Over the last 2 weeks, how often have you felt nervous, anxious or on edge?"). The GAD-7 is a reliable and valid scale, with a Cronbach's alpha of 0.91 in this sample. A cut-off value of ≥10 was used to classify patients with clinically relevant anxiety symptoms [26]. The 9-item Patient Health Questionnaire (PHQ-9) was used to measure *depressive symptoms*. The items of this questionnaire mirror each of the 9 DSM-IV depression criteria and are answered on a 4-point Likert scale from 0 'not at all' to 3 'nearly every day' (e.g. "Little interest or pleasure doing things"). The PHQ-9 is a reliable and valid measure of depressive symptoms [27], with a Cronbach's alpha of 0.83 in the current sample. A cut-off score ≥ 10 was used to classify patients with clinically relevant symptoms of depression. The 14-item Type D Scale (DS14) was used to measure *Type D personality* (i.e. tendency towards negative affectivity and social inhibition [28]). The items on this scale are rated on a 5-point Likert scale ranging from 0 'false' to 4 'true' and can be divided into a 7-item negative affectivity subscale (e.g. "I am often irritated") and a 7-item social inhibition subscale (e.g. "I find It hard to start a conversation"). Type D personality is defined as a score of ≥10 on both subscales [28]. Cronbach's alpha was 0.88 for the negative affectivity subscale, and 0.85 for the social inhibition subscale in the current sample.

Patients' beliefs about their heart failure were measured using official non-modified translations of the first eight items of the B-IPQ [29]. Items (e.g. 'How much does your illness affect your life?', 'How concerned are you about your illness?', and 'How well do you think you understand your illness?') are rated on an 11-point Likert scale, and total scores range from 0 to 80. Higher scores reflect a more threatening view of heart failure. This questionnaire has good psychometric properties in patients with heart failure [30], and Cronbach's alpha in the current sample was 0.69.

Patient-reported causes of heart failure were measured with the ninth item of the BIPQ [29]. This is an open-ended question where patients themselves have to report the three most important causes of their disease (i.e. 'Please list in rank-order the three most important factors that you believe caused your illness. The most important causes for me: 1) … 2)… 3)…'). To analyze this item, the coding scheme from Duwe et al. [31] was used. Using both inductive and deductive thematic analyses, they established the following categories in a sample of older patients with hypertension: physical (e.g. diabetes mellitus), natural (e.g.

Table 1
Distribution of causal illness attributions of heart failure using the coding scheme of Duwe et al. [31], and the three most frequent reported causes per category.

Type of cause	% (N) of patients reporting cause ($N = 529$)[a]
Physical cause	**241 (46%)**
• Comorbidities (e.g. diabetes mellitus, lung disease, renal disease and hypertension)	159 (30%)
• Myocardial infarction	38 (7%)
• (Over)weight	39 (7%)
Natural cause	**171 (32%)**
• Hereditary, familial	86 (16%)
• Genetics, congenital	69 (13%)
• Aging	24 (5%)
Behavioral cause	**203 (38%)**
• Smoking	107 (20%)
• Physical activity levels	55 (10%)
• Alcohol use	40 (8%)
Psychosocial cause	**187 (35%)**
• Stress	106 (20%)
• Work related stress	73 (14%)
• Anxiety (and related symptoms)	19 (4%)
Supernatural cause	**9 (2%)**
• Bad luck	4 (1%)
• There is no cause	4 (1%)
• Suddenly	1 (0%)
Other cause	**130 (25%)**
• Cause unknown	46 (9%)
• Patient reported symptoms instead of causes	32 (6%)
• Ambiguously interpretable answer	4 (1%)

[a] Patients who did not answer B-IPQ item 9 ($N = 66$) are excluded from this overview.

genetics), behavioral (e.g. diet), psychosocial (e.g. stress), supernatural (e.g. God), and other (e.g. do not know) causes [31].

2.3. Statistical analyses

Answers to the ninth item of the B-IPQ were independently coded by two authors (HV and IT), based upon the coding scheme proposed by Duwe et al. [31]. Distribution of answers over (sub)categories are shown as frequencies with percentages. Second, descriptive statistics were calculated for demographic, clinical and psychological characteristics for the total sample and stratified by causal subgroups. Medians with interquartile ranges (IQR) are reported for continuous variables, and frequencies with percentages for categorical variables. To compare patients who do or do not report a certain cause of heart failure (e.g. patients reporting physical causes versus patients not reporting physical causes) on demographic, clinical and psychological characteristics, Fisher's exact tests were used for categorical variables, and Mann Whitney-*U* tests for continuous variables. Finally, multivariable logistic regression analyses were performed to examine associations between patient-reported heart failure causes and psychological outcome measures (i.e. poor health status, distress, threatening illness perceptions and poor self-care behavior). All tests were two-tailed and a *p*-value of <0.05 was used to indicate statistical significance. All analyses were performed using SPSS 22.0 for Windows (SPSS Inc., Chicago, IL, USA).

3. Results

3.1. Patient characteristics

Of the 595 patients, 66 patients (11%) did not answer the ninth B-IPQ question about causes of their disease and were excluded from further analyses. The remaining patient sample ($N = 529$) was more likely to be higher educated (63% versus 40%, $p < 0.001$) and to participate in cardiac rehabilitation (23% versus 8%, $p = 0.009$) compared with the excluded patients. There were no other between-group differences on the baseline characteristics. The total study sample ($N = 529$) had a median age of 65 years (IQR = 58–73), 79% was male and 63% had a tertiary educational level or higher. Median LVEF was 27% (IQR = 22–31). Regarding the psychological characteristics, 16% reported clinically relevant anxiety symptoms, 20% reported clinically relevant depressive symptoms, and 20% was classified as having a Type D personality.

Table 2
Sample characteristics stratified by physical, behavioral, psychosocial and natural attributions.

	Physical cause			Natural cause			Behavioral cause			Psychosocial cause		
	Yes ($N = 241$)	No ($N = 288$)	p	Yes ($N = 171$)	No ($N = 358$)	p	Yes ($N = 203$)	No ($N = 326$)	p	Yes ($N = 187$)	No ($N = 342$)	p
Socio demographics												
Age (years), median (IQR)	54 (57–71)	65 (59–74)	0.58	65 (54–73)	65 (59–73)	0.52	**64 (55–71)**	**66 (60–73)**	**0.02**	64 (57–72)	66 (59–73)	0.17
Male, N(%)	**180 (75)**	**291 (82)**	**0.02**	133 (78)	338 (80)	0.58	**177 (87)**	**294 (75)**	**<0.001**	**160 (86)**	**311 (76)**	**0.008**
Having a partner	**191 (79)**	**198 (69)**	**0.006**	**137 (80)**	**252 (70)**	**0.02**	142 (70)	247 (76)	0.14	132 (71)	257 (75)	0.26
High educational level	**163 (68)**	**170 (59)**	**0.04**	109 (64)	224 (63)	0.79	138 (68)	195 (60)	0.06	125 (67)	208 (61)	0.17
Heart disease characteristics												
Ischemic etiology	133 (55)	168 (58)	0.47	94 (55)	207 (58)	0.54	**143 (70)**	**158 (49)**	**<0.001**	**127 (68)**	**174 (51)**	**<0.001**
LVEF (%)[a]	26 (22−30)	28 (22−31)	0.14	27 (21−32)	27 (22–30)	0.67	**29 (23−30)**	**26 (30−31)**	**0.02**	28 (22–30)	27 (21−31)	0.66
Comorbidities												
Hypertension	137 (57)	167 (58)	0.79	102 (60)	202 (56)	0.48	115 (57)	189 (58)	0.76	**122 (65)**	**182 (53)**	**0.007**
Anemia	22 (9)	30 (10)	0.62	11 (6)	41 (12)	0.07	19 (9)	33 (10)	0.77	19 (10)	33 (10)	0.85
Lifestyle												
Smoking	**23 (10)**	**60 (21)**	**<0.001**	33 (19)	50 (14)	0.12	38 (19)	45 (14)	0.13	**40 (21)**	**43 (13)**	**0.008**
Self-care behavior[b]	25 (18–31)	25 (20−32)	0.08	25 (19–32)	25 (19–31)	0.97	24 (20−32)	25 (19–31)	0.58	25 (20−33)	24 (19–31)	0.08
Psychological status												
Anxiety[c]	33 (14)	48 (17)	0.35	26 (16)	55 (16)	0.99	31 (16)	50 (16)	0.99	**38 (21)**	**43 (13)**	**0.02**
Illness perceptions[d]	42 (34–47)	40 (32–47)	0.25	39 (32–47)	41 (33–47)	0.43	**40 (31–46)**	**41 (33–48)**	**0.01**	40 (32–46)	41 (33–48)	0.52
Treatment												
Psychotropic medication[e]	38 (16)	43 (15)	0.80	24 (14)	57 (16)	0.56	36 (18)	45 (14)	0.21	**39 (21)**	**42 (12)**	**0.009**

P's < 0.10 are reported in this table, significant results ($p < 0.05$) are printed in bold.
Results presented as N(%) for categorical variables, and as median(interquartile range) for continuous variables.
[a] LVEF (%): left ventricular ejection fraction, reported in percentages.
[b] Self-care behavior: total score European Heart Failure Self Care Behavior Scale (higher scores indicate worse self-care behavior).
[c] Anxiety: Generalized Anxiety Questionnaire > 10.
[d] Illness perceptions: total score brief Illness Perception Questionnaire (higher scores indicate a more threatening view of illness).
[e] Psychotropic medication: use of antidepressants, anxiolytics and/or hypnotics.

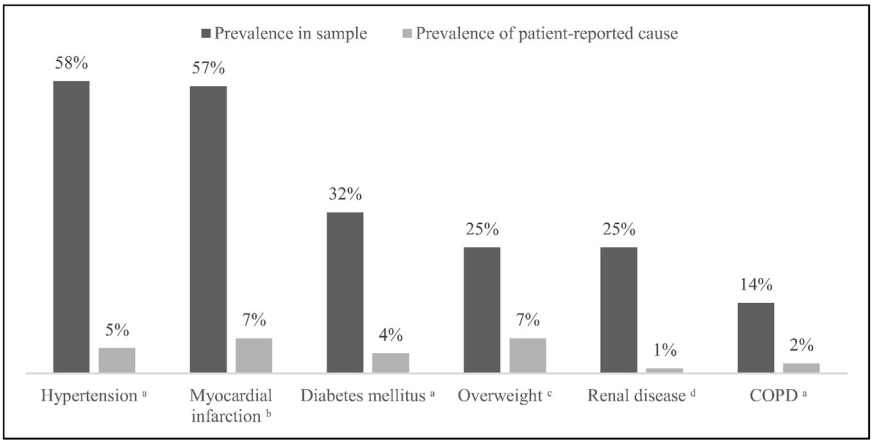

Fig. 1. Prevalence of clinical risk factors as compared to patient-reported causes. [a]Prevalence in sample based on comorbidity report in medical records and patient questionnaires. [b]Prevalence in sample based on proxy measure 'ischemic heart failure etiology'. [c]Prevalence in sample based on body mass index >30. [d]Prevalence in sample based on glomerular filtration rate < 60 ml/min/1.73 m^2 in medical record.

3.2. Coding of patient-reported causes for heart failure

Coding of patient-reported causes in 529 patients with heart failure, according to the coding scheme proposed by Duwe et al. [31], led to 16 discrepancies between two independent coders. Hence, the agreement rate was high (i.e. $(1-(16/529)) * 100 = 97\%$). After discussion, all discrepancies were resolved and full agreement was reached. All answers were coded into the following categories: *physical causes* (i.e. comorbidities, myocardial infarction, overweight, hypertension, medical treatment, medical error, cholesterol, viral or bacterial infection), *natural causes* (i.e. heredity, congenital, aging), *behavioral causes* (i.e. smoking, physical activity levels, alcohol use, lifestyle, self-neglect, non-adherence, diet, environmental exposure and drugs), *psychosocial causes* (i.e. stress, work related stress, anxiety, family related stress, fatigue, personality, depression, life events), *supernatural causes* (i.e. bad luck, no cause, suddenly) and *other causes* (i.e. do not know/understand, no understanding of question, ambiguous answer).

3.3. Patient-reported causes of heart failure

Of the 529 patients, 136 (23%) reported one cause, 103 (17%) reported two causes, 261 (44%) reported three causes, and 29 (5%) reported more than three causes. Most patients (43%) reported causes within one category, while 31% and 14% of the patients reported causes within two or three categories, respectively. Distribution of patient-reported causes stratified by categories together with the three most frequently reported causes per category are presented in Table 1. Most patients (46%) reported physical causes (mainly comorbidities), followed by behavioral (38%, mainly smoking), psychosocial (35%, i.e. (work-related) stress) and natural causes (32%, mainly heredity). A small group of patients

Table 3
Associations between heart failure attributions and psychological outcome measures.

	Poor heart failure specific health status[a]			Psychological distress[b]			Threatening view of heart failure[c]			Poor heart failure self-care behavior[d]		
	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
Age < 60 years	1.08	0.68–1.70	0.76	**2.27**	**1.37–3.78**	**0.002**	**1.69**	**1.06–2.68**	**0.03**	**2.09**	**1.33–3.29**	**0.002**
Male	0.77	0.48–1.23	0.27	**0.51**	**0.30–0.86**	**0.01**	0.67	0.42–1.08	0.10	1.60	0.96–2.66	0.07
Having a partner	0.70	0.45–1.08	0.11	0.95	0.58–1.57	0.85	1.09	0.69–1.72	0.71	1.32	0.84–2.09	0.23
High educational level	0.81	0.54–1.21	0.30	0.76	0.48–1.21	0.25	0.80	0.53–1.20	0.28	**0.55**	**0.37–0.083**	**0.004**
Ischemic etiology	1.37	0.91–2.06	0.13	1.02	0.64–1.63	0.93	1.03	0.67–1.58	0.89	1.02	0.68–1.54	0.93
QRS duration >120 ms	1.09	0.74–1.60	0.68	0.83	0.53–1.30	0.42	0.77	0.51–1.15	0.20	0.78	0.53–1.16	0.22
NYHA class III	**2.68**	**1.80–3.97**	<**0.001**	1.56	0.99–2.47	0.06	**1.75**	**1.16–2.65**	**0.008**	1.09	0.72–1.65	0.68
Comorbidities[e]	1.28	0.97–1.68	0.08	1.07	0.77–1.48	0.69	1.03	0.77–1.38	0.85	1.00	0.75–1.32	0.98
Atrial fibrillation	1.04	0.68–1.59	0.87	1.34	0.81–2.20	0.25	0.88	0.55–1.39	0.57	0.70	0.45–1.10	0.12
Heart failure risk factors[f]	**1.33**	**1.04–1.71**	**0.03**	1.03	0.77–1.36	0.86	1.08	0.84–1.40	0.55	1.24	0.97–1.59	0.09
Psychological history[g]	1.19	0.74–1.92	0.48	**2.57**	**1.53–4.30**	<**0.001**	1.18	0.71–1.96	0.52	0.84	0.51–1.40	0.51
Type D personality[h]	**2.45**	**1.55–3.86**	<**0.001**	**4.32**	**2.67–6.98**	<**0.001**	**2.63**	**1.67–4.13**	<**0.001**	1.59	1.00–2.52	0.05
Physical attributions	1.41	0.95–2.09	0.09	1.14	0.73–1.80	0.56	1.13	0.76–1.70	0.54	0.74	0.50–1.11	0.14
Behavioral attributions	0.81	0.53–1.24	0.33	0.93	0.56–1.52	0.76	0.64	0.40–1.01	0.06	0.84	0.55–1.30	0.44
Psychosocial attributions	1.02	0.67–1.57	0.92	1.54	0.94–2.51	0.09	0.83	0.53–1.32	0.44	1.15	0.75–1.78	0.53
Natural attributions	1.34	0.90–2.08	0.15	0.94	0.58–1.53	0.80	1.06	0.69–1.65	0.78	1.16	0.77–1.76	0.48

Significant results ($p < 0.05$) are printed in bold.
[a] Poor health status: total score Kansas City Cardiomyopathy Questionnaire < 50.
[b] Psychological distress: anxiety (Generalized Anxiety Questionnaire > 10 and/or depression (Patient Health Questionnaire > 10).
[c] Threatening view of heart failure: total score brief Illness Perception Questionnaire ≥ 46.
[d] Poor heart failure self-care behavior: total score European Heart Failure Self Care Behavior Scale > 29.
[e] Comorbidities: sum score of Chronic Obstructive Pulmonary Disease, Diabetes Mellitus and Renal disorder.
[f] Heart failure risk factors: sum score of hypertension, obesity and smoking.
[g] Psychological history: use of psychotropic medication and/or treatment for psychological problems.
[h] Type D personality score of >10 on both negative affectivity and social inhibition subscales of Type D scale.

reported not knowing or understanding what caused their heart failure (9%), and 6% of the patients seemed to have misinterpreted the question (e.g. reported symptoms of heart failure instead of causes).

3.4. Correlates of patient-reported causes of heart failure

Table 2 shows significant group differences on socio demographic, clinical and psychological characteristics for patients who did versus did not report physical, natural, behavioral and psychosocial heart failure causes. The categories 'supernatural' and 'other' were excluded from further analyses due to a small number of cases and a large heterogeneity within the category, respectively.

Patients reporting *physical causes* were more likely to be female, to have a partner, and to be higher educated, but less likely to smoke compared to patients reporting no physical causes. Surprisingly, there were no significant correlations between physical patient-reported causes and heart failure risk factors reported in the medical records. This is confirmed in Fig. 1, showing that physical heart failure risk factors and comorbidities were relatively common in the current sample according to the medical records, while only a small group of patients reported them as a cause of their heart failure; e.g. 58% of the sample suffers from hypertension, while only 5% recognizes and reports hypertension as a cause of heart failure.

Patients reporting *natural causes* were more likely to have a partner compared to patients reporting no natural causes. Patients reporting *behavioral causes* were younger, more likely to be male and to have an ischemic etiology of heart failure, have a higher median LVEF, but a less threatening view of their heart failure compared to patients reporting no behavioral causes. Finally, patients reporting *psychosocial causes* were more likely to be male, and to have an ischemic etiology of heart failure, hypertension and anxiety, to smoke and to use psychotropic medication compared to patients reporting no psychosocial causes.

There were no between group differences on NYHA functional class, health status, diabetes mellitus, chronic obstructive pulmonary disease, renal disease, anemia, body mass index, alcohol use, self-care behavior, depression, Type D personality, psychological treatment and cardiac rehabilitation participation between patients reporting physical, natural, behavioral and psychosocial causes and patients not reporting these causes.

3.5. Patient-reported causes and other patient-reported outcomes

Multivariable logistic regression analysis showed no significant associations between the causes that patients report for their heart failure and heart-failure specific health status, psychological distress, having a threatening view of heart failure, or self-care behavior. However, there were trends towards associations between physical causes and poor health status (odds ratio (OR) = 1.41, 95% confidence interval (CI) = 0.95–2.09, $p = 0.09$), between psychosocial causes and psychological distress (OR = 1.54, 95% CI = 0.94–2.51, p = 0.09), and between behavioral causes and a less threatening view of heart failure (OR = 0.64, 95% CI = 0.40–1.01, $p = 0.06$) (Table 3).

4. Discussion

To the best of our knowledge, this is the first study to examine patient-reported causes and their correlates in heart failure patients. In our large European heart failure cohort, patients most frequently reported physical causes, followed by psychosocial, behavioral and natural causes. Within these categories, comorbidities, (work-related) stress, smoking and heredity were most often mentioned. Men were more likely to report behavioral and psychosocial causes, compared to women. This might be explained by the finding that women are more likely to participate in health prevention strategies like reading health promotion material [32]. Patients with partners more often reported physical and natural causes compared to patients without a partner, possibly indicating that partners may play a supportive role in patients' understanding of conventional heart failure risk factors. Finally, patients with ischemic heart failure were more likely to report behavioral and psychosocial causes compared to patients with non-ischemic heart failure. This is in concordance with popular beliefs about ischemic heart failure, and the increasing awareness of the detrimental effects of stress, deriving from a Western lifestyle [33].

In line with previous research in other disease populations, there was a relatively large discrepancy between the prevalence of physical risk factors and comorbidities according to the medical files and the patient-reported causes. This indicates that patients with heart failure might not recognize or underestimate their physical risk, which is emphasized by our finding that a relatively large subgroup of patients did not report any cause at all. These patients tended to have a lower education level and were less likely to participate in cardiac rehabilitation. As insight into the risk factors for disease development is a prerequisite for patients to develop ideas about disease causes and a precondition to take action, education on risk factors is key [34]. For people who already suffer from heart failure, cardiac rehabilitation could offer support in tackling and educating on modifiable risk factors [35]. However, attendance is related to disease perception; patients who feel to understand their disease and consider it to be controllable, symptomatic, and with severe consequences, are more likely to attend rehabilitation programs [36]. This underlines the need for healthcare professionals to discuss patients' illness perceptions during the initial heart failure consultations. With regard to primary prevention, national, community, and school-based media and educational campaigns seem effective in enhancing knowledge, while broad community-based programs targeting multiple risk factors simultaneously have been less successful [37]. This emphasizes the importance of focused information provision (e.g. on tobacco use) for target audiences at risk (e.g. lower educated people).

There were some trends towards associations between patient-reported causes for heart failure and health status, psychological distress and illness perceptions. Contrary to our hypothesis based on Leventhal's common sense model, we found no association between patient-reported causes and self-care behavior. This might be due to the coding scheme that did not take patients' attributional style into account. According to the attribution theory [42], someone's attributional style is determined by his/her tendency to characterize (the cause of) their successes and failures (e.g. diseases) as internal/external, stable/unstable, and controllable/uncontrollable [38]. A meta-analysis of 27 studies in individuals coping with physical diseases showed that internal, unstable and controllable causes (e.g. lack of exercise) were indirectly associated with positive psychological adjustment to their disease and better self-care behavior through approach- and emotion-focused coping, while stable and uncontrollable causes (e.g. heredity) were indirectly associated with negative psychological adjustment through avoidance-focused coping [39].

Future studies and meta-analyses should examine if patient-reported causes and their impact on self-care behavior and other patient-reported outcomes are affected by the way patient-reported causes are assessed and coded. In the B-IPQ that was used in the current study, patients have to actively report their own ideas on causality, which triggers more complex cognitive processes than closed-ended questions. A think aloud study on the B-IPQ indicated that some patients misinterpreted the open-ended question and reported symptoms instead of causes, or that patients combined causes and consequences in their answers [40]. In our study, 11% of the patients did not answer the question and 6% reported symptoms rather than causes, emphasizing that this question may be challenging for patients to answer. Also, it seems important to take cultural differences into account; e.g., Asians are more likely to report supernatural and psychosocial causes [19,41], while Pakistani-Muslims are more often unable to report any cause compared to Western patients [13]. The majority of our sample consisted of Western-European patients. The small number of Southern-European patients did not enable us to study differences in causal illness attributions between these two regions, which limits the

generalizability of our findings. Another study limitation was the lack of information about duration of heart failure, making it impossible to identify differences in patient-reported causes between recently diagnosed patients and patients diagnosed longer ago.

Despite the limitations, this is the first study examining patient-reported causes of heart failure, showing a considerable variety in causal beliefs which are not necessarily aligned with established risk factors. Health professionals may use initial heart failure consultations as an opportunity to discuss and educate on disease causality. This may enhance patients' understanding of their medical condition which, in turn, may also promote more adequate coping behavior and better self-care of heart failure [42].

Disclosures

The authors report no relationships that could be construed as a conflict of interest.

Registration

The REMOTE-CIED study is registered at ClinicalTrials.gov with study ID NCT01691586.

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